

**Meeting the Needs of People with Disabilities—
New Approaches in the Health Sector**

A technical note

by

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The views expressed in this report are those of the authors and do not necessarily reflect the official position of the World Bank.

Table of Contents

| | |
|---|----|
| 1. Introduction..... | 1 |
| 2. Policy Context..... | 2 |
| 2.1 World Bank Health Sector Objectives | 2 |
| 2.2. Health for All | 3 |
| 2.3 The Legacy of Institutionalization | 4 |
| 3. Community-Based Services | 5 |
| 3.2 Supply of Health Services to People with Disabilities..... | 6 |
| 3.2.1 Prevention..... | 7 |
| 3.2.2 Rehabilitation..... | 8 |
| 3.2.3 Technical Aids and Assistive Devices..... | 9 |
| 3.2.4 Accessibility | 10 |
| 4. Sources of Supply | 10 |
| 5. Costs and Financing | 11 |
| 6. Strategic Choices..... | 13 |
| 6.1 The Widening Service Gap | 13 |
| 6.2 Mainstreaming or Targeted Interventions | 14 |
| 6.3 Community-Based Services | 15 |
| 8. Conclusion | 17 |
| 8.1 Addressing Immediate Needs..... | 17 |
| 8.2 Introducing a Community-Based Strategy..... | 18 |
| 8.3 Changing the System..... | 20 |
| Annexes..... | 21 |
| Annex 1. Current Concepts and Prevalence | 21 |
| Current Concepts | 21 |
| Prevalence of Disablement | 22 |
| Gender and Disability..... | 22 |
| Types of Disability | 23 |
| Future Trends | 24 |
| ANNEX 2. Summarizing Demand Characteristics and Required Service Responses..... | 26 |
| Bibliography..... | 28 |

1. Introduction

Economic and social development measures are key factors in improving health, lengthening life, and improving the quality of life. While development tends to decrease the overall risks of ill health and disablement, people with disabilities are an increasing subgroup as populations age and child survival rates increase.

People with disabilities tend to be disempowered and deprived of economic and social opportunities and security because of social and physical barriers in society. They tend to be poor by all poverty standards—material deprivation, low human development, lack of voice and influence, and acute vulnerability to economic, social, and health risks. Furthermore, they are also underserved by most public and private institutions and services.¹ As a result, people with disabilities tend to be the poorest of the poor. Women with disabilities in particular are vulnerable to poverty because they often have few economic means and may resort to begging for survival.

The many faces of poverty—such as inadequate nutrition, unsanitary water and facilities, unsafe living and working conditions, limited access to reproductive health services and safe motherhood, lack of information and economic resources, and unavailability of health and social welfare services and protection—are major risk factors for preventable illnesses and resulting disabilities. At the same time the direct cost of illnesses and temporary or permanent disability increase the risk of falling into poverty. Poverty, poor health conditions and their disabling effects, high health care costs, and diminished earning capacity are linked. Indeed, disability is a main cause of poverty in countries that have limited or nonexistent social protection systems.² In Tanzania, for instance, households that had a member with a disability had a consumption level of less than 60 percent of the average.³

¹ For more on the status of people with disabilities, see Einar Helander, *Prejudice and Dignity—An Introduction to Community-Based Rehabilitation*, 2nd edition (New York: United Nations Development Programme, 1999) Available online at: http://dag.virtualave.net/p_d.htm. See also Ann Elwan, *Poverty and Disability—A Survey of Literature*, Social Protection Discussion Paper No. 9932 (Washington, D.C.: World Bank, 2000). Available online at: <http://www.worldbank.org/sp/>.

² Even in countries with long history of social protection the total incomes of people with disabilities are only a fraction of the non-disabled population. For instance, in 1997 the median income of people with disabilities in the United States was about one-fifth of the income of employed, nondisabled people. The employment rate of people with disabilities people was 50 percent, whereas the employment rate of the nondisabled working population was 78 percent. See: <http://www.census.gov/hhes/www/disable/emperndistbl.pdf>.

³ Howard White, “Africa Poverty Status Report,” 3rd draft, In “Ability, Poverty and Development—An Issues Paper,” Department for International Development, United Kingdom (2000). Available online at: <http://www.dfid.gov.uk/Pubs/files/disability.pdf>.

The role of the health sector in the prevention of disabling conditions, in addressing disabling diseases and limiting their effects, as well as in rehabilitation is central. Therefore, health sector interventions should address the disability dimension to best facilitate poverty reduction.

Approaches to analyzing health risks, service supply and demand, and the performance of the health care sector from a disabled people's perspective will require a framework that goes beyond the health sector and the traditional medical approach to disabilities. Community-based approaches that are integrated into primary health care (PHC) strategies and "Education for All" programs are often cost-effective alternatives to disability-targeted projects specifically.⁴ However, such cross-sector approaches require a medium- or long-term investment not only in policy development and management structures and capacity, but in community participation and empowerment of people with disabilities.

The number of people with disabilities is growing fast. The service gaps are wide and growing. Disability-specific interventions can only reach and benefit a minority of disabled people who are in need of curative and rehabilitative services. This note aims to introduce perspectives, concepts, and guidelines that may facilitate the effective inclusion of a disability dimension in health sector development plans and operations.

2. Policy Context

Disability issues are linked to poverty and social development and therefore should be an integral part of the human development agenda. Although the number of people with disabilities is increasing worldwide, adequate disability policies and their implementation and enforcement remain elusive. This section provides an overview of outdated policies and concepts of disability and proposes more viable alternatives that have been successful at the project level.

2.1 World Bank Health Sector Objectives

The World Bank is the world's largest development investor in the health, nutrition, and population field. The Bank's objectives in this sector are to help client countries:

- Improve the health, nutrition, and population outcomes of the poor and protect the population from the impoverishing effects of disease and high fertility.
- Enhance the performance of health care systems by promoting equitable access to preventive and curative health, nutrition, and population services that are affordable, effective, well-managed, of good quality, and responsive to clients' needs.

- Secure sustainable health care financing by mobilizing adequate levels of resources, establishing broad-based risk pooling mechanisms, and maintaining effective control over public and private expenditure.⁵

Each objective can be made more effective by ensuring that principles of access and the inclusion of people with disabilities are explicit in all policies and programs within health, nutrition, and population sector interventions. These interventions should also be delivered through multiple community partner and interagency collaboration. The Bank’s objectives can be made more effective by explicitly including prevention measures in sector operations.

2.2. Health for All

The international development goals for health are anchored in the “Health for All” strategy of the World Health Organization. The strategy was originally outlined in the Alma Ata document of 1978 and has since been updated and adapted to guide health policies in all United Nations Member States.⁴ It states that primary health care is the most appropriate and cost-effective strategy for better health for all. The primary health care strategy shifts the focus from specialized tertiary care to primary community-based services as the best provider of preventive and curative services. This approach would require:

- Organizing health services with an emphasis on balancing preventive, promotive, curative, and rehabilitative efforts in the communities.
- Applying a participatory approach in partnership with the government, the business sector, nongovernmental organizations, community-based organizations, and clients and their families.

Although policies in developing countries generally emphasize the primary health care strategy, the implementation capacity is often weak. Several obstacles hamper the reorientation of an existing health care system toward the PHC model. These obstacles include poor physical infrastructure, urban-biased allocation of resources, a mismatch of supply and demand, centralized service and administrative structures, health care providers of varying skill levels, and scarcity of financial, technical and human resources. In particular, there tend to be gaps in the provision of rehabilitation and mental health services.

People with disabilities are seriously underserved by all social sector services, including the health care service system. In Namibia, for instance, most people with disabilities, especially those in rural areas, have no access to rehabilitation services. Furthermore, there are serious exclusion errors in the social protection system, even when benefits are intended to cover all eligible individuals.

⁴ See http://www.who.dk/eprise/main/WHO/AboutWHO/Policy/20010827_1.

Table 1. Rehabilitation Services and Disability-Related Social Protection in Namibia

| | |
|--|-----------|
| Total population | 1,410,000 |
| People with disabilities | 43,800 |
| Percentage of total population | 3.1 |
| Percentage of people with disabilities who receive rehabilitation services | |
| In urban areas | 15 |
| In rural areas | 2 |
| Percentage of blind people who receive a Blind Persons Grant | 1 |
| Percentage of people with disabilities who receive a Disabled Persons Grant | 27 |

Sources: Namibian Census, “The Green Paper on Developmental Social Welfare Policies in Namibia” (1997). And Kalinidhi Subbarao, “Namibia’s Social Safety Net—Issues and Options for Policy Reform,” World Bank (1996).

Specialized and technology-intensive service concepts cannot effectively meet the enormous unmet service needs related to disability. Community-based rehabilitation (CBR) strategies have been developed as viable options for addressing the causes and consequences of disablement and reaching a wider segment of the disabled population (table 1). Community-based rehabilitation uses the primary health care approach and should be an integral part of the PHC strategies and structures to reach those in need, to benefit from synergies, and to avoid duplication and costly parallel structures.

2.3 The Legacy of Institutionalization

The lives and opportunities of people with disabilities have been and still are largely determined by the attitudes of nondisabled people. The perceived needs of people with disabilities have been served based on the widespread notion of what disability is and how much disabled people are different or special.

In the former Soviet Union, a discipline of “defectology” focused on classifying people in disability categories to determine the appropriate institution for each person. For children with disabilities one medical diagnosis determined a lifetime destiny. This medical model of disability has often led to an emphasis on “treatment” in special centers that are operated by the ministries of health or social welfare. Although concepts and practices are evolving, institutionalization is still widely practiced in both developing and industrial countries.

The narrow, medical approach has resulted in medicalization, institutionalization, and over-professionalization of disability issues and questionable solutions with very low coverage, high unit costs, and poor outcomes from the rehabilitation and integration perspective (box 1).

The underdevelopment of services for disabled people is a systemic problem and calls for a comprehensive review of human development sector services and their performance, cooperation, division of labor, and financing arrangements.

Box 1. Comparison of costs between community-based services and institutional services

In March 1998 the World Bank compared the costs of childcare in Romania and found that state residential institutions cost much more than community residential care, foster care, or adoption or family reintegration. State residential institutions costs were US\$214–298 per child per month, \$105–141 for community residential care, \$96 for professional foster care, \$48 for voluntary foster care, and \$20 for adoption or family reintegration.

In Lithuania community services for the elderly, such as home visits, meals, medical care, and other assistance, were estimated to be 25 percent of the cost of residential care. An enriched dayschool program for children with disabilities, including education, two meals a day, job training, and transportation, no more expensive than residential care.

In Armenia, educating a child in a residential boarding school is 10 times more expensive than a regular school education.

Source: David Tobis, “Moving from Residential Institutions to Community-Based Services in Eastern Europe and the Former Soviet Union,” World Bank (1999).

3. Community-Based Services

People with disabilities need access to the same basic health services as other population groups. However, people with disabilities are exposed to greater health risks than the nondisabled population groups because of poorer living conditions, low incomes, and poverty. The type of health services required by disabled people can be targeted toward two groups—those with disabilities that are caused by other health problems and those with a specific disability alone. Both groups need a basic health care package that is available at the community level and a referral system for more demanding services. (Basic services related to disability are generally not automatically available at the community level as part of the health care system.)

The health sector should be prepared to meet the demand for prevention programs, curative interventions, such as corrective surgery and medical rehabilitation, and assistive devices, particularly orthoses and prostheses. Specific disability-related health services require some level of specialized knowledge that is not part of standard health sector training. In accordance with the primary health care strategy, the basic health service package should be available at the community level. If general health services are inaccessible, inappropriate, or unaffordable by people with disabilities, the demand for general services may flow into the

more expensive system of special services. Often services are beyond the reach of most people with disabilities, especially those in developing countries, leaving them with no access to needed services.

3.1 Demand for Disability-Related Services

The demand for disability-related health services falls into four categories—preventative services, curative services, rehabilitation, and technical assistive devices. These simple classifications may be elaborated on with descriptions of the services by type of disability or disabled person the service is intended to target. For instance, some services include rehabilitation centers for the blind or special schools for the deaf. However, attempts to provide services should be preceded by comprehensive analysis of needs to avoid interventions that solve one problem, but create another. Rehabilitation of a landmine victim without ensuring the provision of adequate orthopedic equipment is not enough to make the person more independent and productive.

In 2001 the World Health Organization created the “International Classification of Functioning, Disability and Health” (ICF), new global standard of disability concepts that is based on a multidimensional concept of disablement. The ICF classification can be used to describe disability demand patterns in more detail and to determine if the service will be an issue of a chain of subsequent types of demand over a person’s lifetime or a shorter “disablement cycle.” (See Annex.)

3.2 Supply of Health Services to People with Disabilities

The supply of health care services for people with disabilities should be seen in a wider and integrated perspective. From the client’s perspective one single service is typically insufficient; a chain or continuum of services that includes both health care and services in other sectors is required to meet the comprehensive needs of the disabled. Any strategy must recognize the roles and interaction of various sectors and types of services that make up an effective intervention strategy. For instance, early detection of disabilities can be integrated in primary education through quite simple training of teachers and functioning cooperation with primary health care agencies.⁵ Functional training of children with intellectual and sensory disabilities can be integrated into the mainstream education system instead of being provided through facilities that specialize in rehabilitation.

⁵ Ture Jonsson and Ronald Wiman, “Education, Poverty and Disability in Developing Countries,” *Poverty Reduction Sourcebook*, World Bank (2001).

The health sector can, however, have a lead role in the supply of the following types of services:

- Prevention and early detection.
- Curative services, including surgical and orthopedic services.
- Provision of technical aids.
- Medical rehabilitation and support of community-based rehabilitation.
- Specialization and on-the-job training of doctors and other staff.

3.2.1 Prevention

Prevention of disabling living conditions is a general societal concern and responsibility of all sectors. Health care has a specific role in the prevention of impairments that may lead to disabilities.

Prevention means actions aimed at preventing the occurrence of physical, intellectual or sensory impairment (primary prevention) or at preventing impairments from causing a permanent functional limitation or disability (secondary prevention). Prevention includes: Provision of PHC services, prenatal and postnatal care, education in nutrition, immunization campaigns, measures to control endemic diseases, safety regulations, prevention of accidents (traffic safety, occupational safety), and environmental health.⁶

The adequacy of prevention programs in the country context has to be analyzed within a wider framework than in the context of health sector interventions alone. The following list contains some examples of prevention issues. (The World Health Organization's Violence and Injury Prevention Web site provides more specific information.)

Prevention of disabling conditions

- Environmental health.
- Living conditions.
- Working conditions.
- Poverty reduction and alleviation.

⁶ United Nations Development Programme, *Standard Rules on the Equalization of Opportunities for Persons With Disabilities* (New York: United Nations, 1993).

Primary prevention of illnesses

Polio, leprosy, malaria, bilhartsia, trachoma, glaucoma, psychiatric disorders, tuberculosis, human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS).

Prevention of injuries

- Occupational safety.
- Traffic safety.
- Prevention of violence.
- Landmine awareness and clearance.

Prevention of malnutrition

- Vitamin A deficiency.
- Iodine deficiency.
- Marasmus.
- Kwashiorkor.

Prevention of misuse of alcohol, drugs and tobacco

- Preventing direct disabling effects.
- Preventing indirect effects in infants.

3.2.2 Rehabilitation

The term rehabilitation refers to a process that aims to help people with disabilities reach and maintain their optimal physical, sensory, intellectual, psychiatric, and social functional levels, thus providing them with the tools to live more independently.

Rehabilitation may include measures to provide and/or restore functions or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation does not involve initial medical care. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation.⁷

Most of the rehabilitation services that are available in developing countries are specialized according to particular disabilities—such as rehabilitation for the blind, for the deaf, or for people with physical or mental disabilities. Typically these services are operated by the government or nongovernmental organizations that may be supported by external partner

⁷ United Nations Development Programme, *Standard Rules*.

organizations and tend to provide only partial services, to have an urban bias, and to be unevenly distributed regionwide.

3.2.3 Technical Aids and Assistive Devices

Assistive devices are used to compensate or complement functional limitations. The range of sophistication stretches from homemade crutches and walking aids to high-tech devices. Assistive devices can be classified based on their functions in helping individuals perform activities of daily life:

- Personal care and protection.
- Personal mobility.
- Housekeeping.
- Home adaptation.
- Communication, information, and signaling.
- Handling.
- Environment improvement.
- Recreation.
- Therapy and training.
- Orthotic and prosthetic devices.

In developing countries several barriers impede the supply of cost-effective technologies for people with disabilities:

- The high cost of technologies may not be appropriate in a developing country.
- The personnel using the technologies may not be knowledgeable enough to use the equipment in everyday situations.
- There may not be a reliable supply of spare parts and repair services.
- There are not enough specialized doctors and hospitals to make full use of high-quality technology.
- Rehabilitation, education, and working conditions do not fully support the choice of technology.

Although imported technology may appear to be a solution, it is often expensive, difficult to service locally, and possibly unsuitable to local culture or conditions. Therefore, policies should facilitate the indigenous production of assistive devices by using existing industrial structures as the supply base to ensure sustainability. For instance, wheelchair and tricycle production that is integrated into a local bicycle business is far more appropriate than specialized wheelchair factory production of imported models that rely on imported parts.

3.2.4 Accessibility

The usability of health service facilities and services by disabled people requires accessibility (box 2). Universal Design or Design for All (DfA) refers to environments, products, technology, and services that have been planned and designed to be usable by a wide and diverse population without additional features or with only minor adjustments.⁸ Universal design and assistive technology are complementary strategies that aim to help people with disabilities better interact with and orient themselves in the daily environments. Poor planning and design can create or increase a need for assistive devices.

Although producers of goods and services are increasingly introducing accessibility as a criterion, the practice is still rare, particularly in developing countries. The costs induced by architectural barriers or poor design tend to fall on disabled consumers or the public sector. Accessibility is largely a public good and its implementation usually requires public intervention. International donors should not export goods and services that are not up to standards.⁹ Therefore, accessibility should be an obvious basic policy for donor agency projects.

Box 2. Minimum accessibility criteria for hospitals and health facilities

- All entrances should be accessible to wheelchair users.
- All rooms should be accessible for the benefit of patients and visitors and staff members with disabilities.
- All clinics on all floors should be accessible.
- All patients' restrooms should be accessible to wheelchair users.
- All administrative departments should be accessible to staff members confined to wheelchairs.

4. Sources of Supply

The supply of health care services for people with disabilities is comprised of a mix of services and projects catered by many individuals, government agencies, and nongovernmental organizations. Comprehensive information on disability-related services is seldom readily available. Therefore, a thorough analysis is an important step prior to any interventions.

The potential role and resources of disabled people and their families and communities tend to remain underutilized as long as the focus is on medical aspects and specialized services.

⁸ “Universal Design” is the term used in the United States and “Design for All” is the European equivalent.

⁹ See www.un.org/esa/socdev/enable/designm/index.html. Perspectives and references to some specific accessibility standards are also presented in “Transport, Poverty and Disability in Developing Countries” and “ICT and Disability in Developing Countries.”

A community-based rehabilitation strategy, on the other hand, explicitly involves people with disabilities and their families and communities as agents of action. (For more information, see Chapter 7.)

In low-income settings the possibility of increasing market-based private services for people with disabilities is small. Although the number of disabled people can be high, the ability to pay for services may be limited. However, some increased supply could be achieved with cooperation between the private and public sectors. For instance, community-based rehabilitation programs and some preventive work could be subcontracted to private nurses, doctors, small health stations, or nongovernmental organizations, particularly those of disabled people themselves (table 2).

Paradoxically, health care systems and health personnel are often unprepared to meet the service demands of disability because of lack of understanding, knowledge, and skills, as well as outdated attitudes and practices. The modern concept of disability is not always a standard component in the training of medical personnel. Improvements in the health sector's response to disability and people with disabilities require an ongoing investment in staff training.

5. Costs and Financing

Financing of the disability-related sector is similar to the institutional and financing structure of a country's health, social protection, and social services. The financing of work-related disabilities can be provided by commercial insurance systems. The poorest and most vulnerable groups are seldom eligible for these services. In most countries the main financial source for disability services is the public sector and general revenues.¹⁰ Public sector involvement is needed to produce adequate services for people with disabilities, because the health care market is vulnerable to market failures, such as monopolies, supplier-induced demand, and goods with externalities.

Although public intervention may ensure protection and access to services, the actual production of services can be done privately or by public agencies. Nonetheless, monitoring mechanisms are needed to ensure that the intended services are delivered to the target population. The public sector can contract with nongovernmental organizations or other private groups to make health care services available to people with disabilities.

¹⁰ Three studies on disability insurance and benefits are available online at: www.worldbank.org/sp/.

Table 2. Model framework for analysis of disability-related services¹¹
 (This table is a template; it contains no data.)

| The roles of: | Producer | Financier | Number of projects | Type and number of beneficiaries | Input indicators | Output indicators |
|---|-----------------|------------------|---------------------------|---|-------------------------|--------------------------|
| Public sector Responsible ministries Local governments National disability committees Private nonprofit sector Organizations of disabled people Organizations for disabled people Cooperatives Co-ops of disabled people Other Business sector Service providers Social responsibility initiatives Voluntary funding initiatives Communities Families People with Disabilities | | | | | | |

Under the purchaser/provider model, third-party payment mechanisms can be designed in any of the following ways:

- Line item model—detailed budgetary transfers are made to a certain program or facility, and the provider is salaried.
- Global budget transfers—flexibility to reallocate across inputs or programs.
- Capitation—periodic fixed amount per insured person makes the total costs predictable and controlled.
- Fee-for-service—no fee schedule.
- Fee-for-service—with a fixed fee schedule.
- Case-based service—predetermined amount covers all services per case or episode.

¹¹ The diversity of disability-related projects makes a project inventory a necessary starting point. For a sample project inventory table see <http://www.worldbank.org/children/design/starting/invent.htm>

Any payment method can create powerful intended or unintended incentives that may affect the provider's behavior and the efficiency of the health services.¹² Payment issues require particular attention in cases where the customer control mechanisms are weak. Poor, disabled people in developing countries are unable to exercise quality control themselves.

The costs of disability-related health care are not independent from the costs of other disability relevant subsectors, such as education and social security. Increases in health care expenditures for disabled clients may reduce the demand for special education and affect social security costs. A holistic, long-term perspective of the cost issue is more appropriate than direct, short-term cost accounting.

6. Strategic Choices

Disability is an issue that attracts many kinds of intervention initiatives by various organizations, resulting in an uncoordinated patchwork of small-scale projects that tend to have marginal coverage and little systemic effects. In the absence of transparent, goal-conscious policies and strategies, the situation is unlikely to improve.

6.1 The Widening Service Gap

Disability services in developing countries fall short of demand in both quantity and quality. The potential demand remains hidden perhaps because of lack of awareness or discouragement from the dearth of services. Demand could also be low because people have low expectations of the benefits of the services, such as the benefits of rehabilitation to disabled girls and women; rehabilitation alone does not lead to improved opportunities for women.

There are over 110 million people with moderate or severe disabilities in the developing countries. About 70 million of them (or 63 percent) need rehabilitation services and the remainder need periodic rehabilitation or simple technical aids (table 3).

The demand for disability-related services is expected to increase rapidly in the next decade for several reasons, such as:

- Recent population growth.
- Increased life expectancy.
- Improved survival rates of children with disabilities.

¹² Howard Barnum et al. argue that the mixed types of provider payment are superior to reliance on any single method. For more information see www.worldbank.org/html/extdr/hnp/hddflash/hcwp/hrwp043.html.

- Epidemiological transition.
- An increase in disabilities from violence, conflict, and accidents.
- Emerging higher incidence of disabling mental conditions.

Scattered disability projects that import technology and expertise will be insufficient to address these challenges. A systemic change in disability management will be essential.

Table 3. Demand for rehabilitation services

| Type of service | Target group | Number in developing countries (in millions) |
|---|---|--|
| Functional training | 30 percent of incidence of severe or moderate disabilities in all age groups. | 45 |
| Special needs education | Children with moderate or severe disabilities aged 5–14 years. | 20 |
| Ability/vocational training | Adolescents with moderate or slight disabilities aged 15–29 years. | 5 |
| Total needing services | | 70 |
| Total number of people with disabilities | | 110 |

6.2 Mainstreaming or Targeted Interventions

The first decision to be made is to what extent to address disability with specific projects or in the context of mainstream operations. The disability dimension have been introduced into development co-operation through three basic strategies:

- Disability-specific projects that target people with disabilities.
- Disability-specific components in mainstream projects.
- Including disability concerns in all aspects of mainstream project planning and implementation in a relevant manner.

These approaches are not exclusive. However, mainstreaming should be the main objective, and disability-specific components in policies and sector programs should be supporting elements of this objective. Isolated disability projects are likely only to support the current donor-dependent patchwork of services that already exists in many countries. Although innovative pilot projects may alleviate poverty of a small target, sustainable funding within the

framework of sector programs is needed to reduce the widespread poverty of people with disabilities and their families.

As there are people with disabilities in all target groups, mainstream projects should be reviewed for their inclusion of a disability aspect. If the project is disability-relevant a several issues must be addressed to ensure that the outcome is not handicapping, that is, discriminating, against people with disabilities. The World Bank disability Web site includes a checklist titled “Rapid Handicap Analysis” (RHA3) provides criteria for assessing the disability relevance of a project and can check a project document for adequacy from the disability perspective.¹³

6.3 Community-Based Services

Access, inclusion, poverty reduction, and equalization of opportunities for people with disabilities cannot be achieved by a single intervention. Disability-related services should be designed to provide a service continuum whose goal is full inclusion. Curative services and medical rehabilitation should be followed by psychosocial and vocational rehabilitation and inclusion in mainstream services and society. Investments in capabilities cannot be realized if services are unable to work in a coordinated.

Box 3. Tripartite project with landmine survivors

A multiyear project, funded by Canadian International Development Authority (CIDA) has been directed to meet the needs of the landmine survivors in Honduras, Nicaragua, and El Salvador. The project is designed to develop community-based rehabilitation in the three host countries through multisector partnerships that include local governments, rehabilitation specialists and facilities, and community organizations, people with disabilities, and their families. A significant focus has been on developing orthotics and prosthetics expertise in the region and promoting a basic knowledge of effective rehabilitation intervention at the individual and community levels. Training programs are also provided in occupational and vocational therapy to develop expertise among the health care providers.

Community-based committees prepared long-term work plans that identified barriers and systemic obstacles that need to be addressed to sustain ongoing support and independent living of people with disabilities. These work plans form the framework for strategic planning to assist the host countries in the development of inclusive and accessible community infrastructures in the short-, medium- and long-term.

¹³ The RHA3 can be accessed through the menu of the site www.stakes.fi/sfa and the World Bank Web site www.worldbank.org/sp/.

Sustainable inclusion of people with disabilities in mainstream society will require:

- Accessibility and “designed for all” mainstream physical environment, technology, products, and services so as not to discriminate against people with activity limitations.
- Access to general and specific services. Specifically, people with disabilities must be aware of and have access to affordable and appropriate medical treatment, rehabilitation, technical aids, and support services. They must also have access to general services and systems, such as schools, housing, health care, and transportation.

The backbone of community-based rehabilitation is the manual titled “Training in the Community for People with Disabilities,” first published by the World Health Organization in 1979 and updated in 1989. Since its publication the manual has given rise to a variety of applications of the same idea.

In 1994 the International Labour Organisation, United Nations Educational, Scientific, and Cultural Organization and World Health Organization agreed on the following definition:

Community-based rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services.¹⁴

There are no halfway solutions to inclusion. Community-based rehabilitation is the root approach to community-level inclusion and integrated disability-related service supply. It aims to address both the accessibility of and access to mainstream society for all disabled people and provide appropriate and affordable services that empower people with disabilities to take charge of their own lives.

The CBR strategy is an offspring of the primary health care strategy, which focuses on a cost-effective use of existing physical and human resources by devolving responsibilities to the community and family level as often as possible. At the same time, a referral system is designed to ensure a chain of services from general services available at the grassroots level to specific services at the national level.¹⁵ For instance, preventive interventions, basic diagnostics, curative services, family-based rehabilitation, and basic access to assistive devices can be made available through a primary health care system and managed in the community. Some diagnostic services and fitting and distribution of assistive devices can be arranged through mobile units.

Clients in community-based rehabilitation programs tend to make more progress than clients in more traditional rehabilitative intervention programs. (The cost-effectiveness of CBR

¹⁴ See <http://www.unescap.org/decade/cbr.htm>.

¹⁵ Helander, *Prejudice and Dignity*, 8.

approaches is still being analyzed by the World Health Organization.) The “Guide to Operations Monitoring and Analysis of Results” can evaluate the results of community-based rehabilitation and is available on the Internet.¹⁶

Box 9 Community-based rehabilitation (CBR)

Community-based rehabilitation initiatives contain several common elements, such as the following:

- Employing a multi-sectoral approach that uses agencies and service providers to respond to the needs of involved disabled people in an integrated “one-stop” manner.
- Decentralizing of resources, functions, and managerial responsibilities to various agencies and actors, such as people with disabilities themselves, families, communities, local organizations, and referral systems.
- Adopting a comprehensive and empowering conceptual framework to disablement.
- Becoming an integral part of community development strategies that consist of several components.
- Integrating rehabilitation services with various health, education, employment, and social services.
- Involving non-professionals in simple rehabilitation techniques.
- Introducing appropriate technology, such as assistive devices that are made widely available and produced in the community from local material.
- Raising awareness and mobilizing communities as a key component of the program.
- Involving the private sector in supplying credits, employment, and technology.
- Giving people with disabilities and their families as clients a central role in the design and follow-up of the program.

8. Conclusion

Health services in developing countries are seldom well-equipped to meet the challenges of disability. In addition, people tend to be biased toward expensive technology and specialization. The service gap is deep and widening.

8.1 Addressing Immediate Needs

Any analysis of the status of people with disabilities in developing countries will reveal that they have obvious, immediate needs, such as:

- Basic awareness and understanding of the current concept of disability.
- Relevant human resources and specific skills in such areas as special diagnostics, including the prevention and early detection of disabilities in children.
- Physiotherapy and psychosocial rehabilitation.

¹⁶ See <http://dag.virtualave.net/omar2.htm>

- Availability of and access to a reliable supply of basic assistive devices, such as orthopedic devices, eyeglasses, hearing and mobility aids, and devices for gastro-urinary tract disabilities.
- Facilities and skills for curative surgery and basic corrective surgery.

The sustainable solution to addressing these obvious needs will require careful consideration because these problems are often systemic and have long historical roots in a country. Rather, comprehensive reform that starts with a participatory review of current policies and structures and leads to a redirected and restructured service delivery system would be the best starting point.

8.2 Introducing a Community-Based Strategy

This section provides a framework for comprehensive sector review and revision in designing a development intervention for sustainable systemic change.¹⁷

In general, the following sequence of activities can be applied to the designing of a disability-related intervention:

- Establishing a task force.
- Situation analysis.
- Policy review.
- Problem definition and prioritizing.
- Choice of strategy.
- Setting objectives and targets.
- Project design.
- Outputs.
- Activities.
- Responsibilities.
- Resources.
- Monitoring and evaluation.
- Management structures.

Establishing a task force. The launching of a situation analysis, policy review, and strategic planning for broad intervention requires a task force or technical committee to assemble brings together a number of the relevant agencies, nongovernmental organizations, and disability organizations. This platform for cooperation is vital to projects that are based in the health sector for establishing the network needed for a functional continuum of care.

¹⁷ Einar Helander and Ronald Wiman, *The Green Paper on Developmental Social Welfare Policies in Namibia*, Ministry for Health and Social Services, Namibia (1997).

Policy review. The task force should formulate and agree on a mission or policy statement that reflects the current internationally-endorsed concepts, principles, and approaches expressed in the “United Nations Standard Rules on Equalization of Opportunities for People with Disabilities” and the “International Classification of Functioning, Disability and Health.”²¹ The existing sector policies and service programs should then be reviewed against this framework.

Situation analysis. A basic analysis should include estimates of the number and status of disabled people (by age and gender, if available) and their living conditions, health status, opportunities and obstacles for participation, and access to mainstream and specific services by disabled people. Involved agencies and organizations, existing programs or projects, budget allocations, personnel resources, qualifications, and existing personnel training should also be examined.

Awareness raising. In disability-related operations awareness of the needs and abilities of people with disabilities is generally weak. An awareness-raising component to support implementation should be designed at an early stage. A training module would help update individuals’ concepts and views on disability as a health issue. Review and revision of the contents of health personnel training may be necessary during the course of the project.

Problem definition and prioritizing. The choice of feasible priorities can be facilitated by consultations among the relevant agencies and groups. A problem-tree analysis that clarifies the interaction of disability with health and other sector issues is a useful input for such consultations. The public health approach may also provide a useful point of departure for identifying health issues that are historically endemic and relevant to disability in the country. The disabling consequences of HIV/AIDS, while often of short duration, should be discussed. However, problem definition and choice of the initial intervention point is typically a political issue.

Choice of strategy. The basic options should combine mainstreaming strategies, community-based, participatory strategies, and disability-specific interventions that may yield visible results rapidly. Interventions that are intensive in professional personnel and imported technology belong to the first-mentioned category. Practical, detailed steps on how to design a community-based rehabilitation strategy and service program are available at http://www.stakes.fi/sfa/helander_cbr.

Setting objectives and targets. For sustainability, human rights, and cost-effectiveness reasons, mainstreaming should be given a high priority in all targeted settings. Even if specific curative or rehabilitative components are needed, a particular mainstreaming component should be included. Gender and child components are also often necessary to equalize access to the project and its benefits for women and children.

Project design. As outputs, activities, resources, and responsibilities are defined, communities, families, and people with disabilities and their organizations should be treated as

a valuable resource base. Detailed menus on how to include disability issues at the various stages of a project cycle can be found in “Disability Dimension in Development Action. Manual on Inclusive Planning.” The publication also contains an auditing tool to establish whether a project plan discriminates against disabled people.¹⁸

Monitoring, follow-up, and evaluation. A roundtable of the main agencies and organizations should be established to follow-up the project. Outcome evaluation criteria can often be based on diagnostic frameworks and made usable with modest training. Such basic tools need to be introduced into the client information system from the beginning.

Management structures. Upgrading disability concerns to a level of priority that ensures meaningful and sustainable results requires a broad approach. A government agency is a useful and often necessary part of effective cooperation and coordination on disability in a country. Programs must be decentralized to ensure access to basic services at the local level and a referral system for progressively more specialized services at the regional level, eventually, national levels. Integration of community-based rehabilitation management systems in the primary health care structures is functional provided that personnel are adequately retrained.

8.3 Changing the System

Sector reforms or nationwide disability programs can improve access to and accessibility of social and health services to people with disabilities. A systemic change would, however, require that all public and private agencies commit and invest in the equalization of opportunities for people with disabilities. First, governments and agencies must commit to equal opportunities for people with disabilities and to the goal of a society for all. Second, the disability dimension must be included in a poverty reduction strategy of mainstream social and economic development goals.

The implementation of a poverty reduction strategy that would reduce poverty and promote the inclusion of disabled people starts by including people with disabilities in the strategy formulation and implementation process from its inception. People with disabilities have played a key role in social and health sector reforms at the national and international levels. Disabled people and disability agencies will, however, need support from the highest levels of government as well as supranational organizations to help build the social and human capital base for reforms at the national and local levels.

¹⁸ The RHA3 can be accessed through <http://www.stakes.fi/sfa> or <http://www.worldbank.org/sp/>.

Annexes

Annex 1. Current Concepts and Prevalence

Disability-related concepts are difficult to grasp because sometimes the differences between ability and disability are ambiguous. Disablement and its definitions and measures are related to particular conceptual, cultural, social, and physical contexts. Indicators and numbers vary depending on the conceptual approach used. Recently, however, a number of international standards on concepts and policy frameworks have been developed.

Current Concepts

The “Standard Rules on the Equalizing of Opportunities for Persons with Disabilities” defines the concept of disability as follows:

The term “disability” summarizes a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.

There are many clusters of concepts in use and many types of indicators used to describe disability. The most common data sets are still based on the “International Classification of Impairments, Disabilities and Handicaps” (ICIDH), which was launched by the World Health Organization in 1980. The ICIDH (1980) defines disability according to the disease model; impairments may lead to disabilities, which lead to handicaps.

This type of classification results in three kinds of data:

- Impairments—deficiencies in bodily, sensory, and mental functions.
- Disabilities—difficulties in performing daily activities.
- Handicaps—the disadvantages that people with disabilities face. Handicaps are not individual characteristics, but refer to the discriminating structures and “rules of the game” in the system’s interaction between the individual and his/her environment.

These concepts allow for the classification of people by disability, but impairment measures tend to give lower figures than indicators that reflect disabilities. And handicaps are difficult to measure. Efforts to describe the incidence and prevalence of disablement and its consequences in a given population make comparative analysis difficult.

In May 2001 the World Health Organization endorsed the “International Classification of Functioning, Disability and Health,” a new global standard of disability concepts based on a multidimensional concept of disablement.¹⁹ The new classification defines social, behavioral, environmental, and physiological/medical disablement according to the specific impairment, the activity and extent of functional limitation, participation in life activities and the duration and quality of such participation, and environmental factors. Although the new international standard is multifaceted it may be used to help measure demand for various types of disability services and craft better, outcome-focused policies.

Prevalence of Disablement

There are many problems associated with gathering data on people with disabilities. The incidence and prevalence of data on disability are difficult to measure because they are often unreliable (underreported or overreported) or unavailable. Consequently, disability data that is valid, reliable, detailed, and comparable is usually not available when needed.

Worldwide prevalence indicators of disability may vary between less than 1 percent to 20 percent. They should be interpreted with caution because the figures reflect not only the cumulative incidence of impairments and their underlying causes, but also differing definitions and operationalizing questions and varying age groups and methods and of data collection.²⁰

“One in ten” is a frequently quoted, but oversimplified, estimate of the prevalence of disability. The crude prevalence rate of serious or moderate disabilities in China in 1987 was 4.8 percent and in Great Britain in 1985 was 8.6 percent. Crude rates can be misleading because the prevalence of disability varies by age. Worldwide prevalence of disability appears in less than 3 percent of individuals below the age of 30, but in over ten percent of those around the age of 60.²¹ Crude estimates of the number of people with disabilities can also be calculated through indirect methods, such as comparisons between age-specific disability prevalence rates to census data.²² Crude rates may be useful for raising awareness, but not for designing policy.

Gender and Disability

Most major disabling illnesses affect men and women at the same rate, but with varying risks. Accidents and violence most affect men; unsafe motherhood conditions are a leading risk for women. High rates of maternal mortality, early marriages, frequent childbearing, poor living conditions, and poor mother and child health care services often lead to disabling conditions,

¹⁹ Available online at: <http://www3.who.int/icf/icftemplate.cfm>.

²⁰ United Nations, “Disability Statistics Compendium,” New York (1990) 26.

²¹ Helander, 22. Available online at: http://dag.virtualave.net/p_d.htm

²² Helander provides age-specific disability prevalence rates for China (1987) and Mali (1976). Although the indirect methods are sensitive to the choice of model rates, they give reasonable global operative figures. See Helander, 25, 39–40. See also Esther Boylan, *Women and Disability* (1991).

such as prolapsed uterus, leg nerve damages, and incontinence. Poor nutrition and anemia are also common. Furthermore, the practice of female circumcision is disabling tens of millions of women.

Overall disability prevalence rates for women tend to be higher than rates for men because of longer life expectancy and differences in age structure. Findings that show clear disability prevalence rates for women and girls may also reflect higher mortality from neglect, malnutrition, and poor health care.²³ In most societies, girls and women who have a disability have a double handicap. Both gender and disability render them vulnerable and subject to discrimination. For a disabled baby girl, exclusion starts at birth when they are at high risk of neglect, malnutrition, and abandonment. Girls are last at the breast, at the table, and to go to school, and women are first to be married and to be divorced, last to be hired, and first to be fired. These combinations lead to an exceptionally high risk of poverty and exclusion for women and girls.

Types of Disability

Although many types of disability exist, classification of disability is necessarily simple. The following table provides estimates of the disability spectrum in a typical developing country. Although estimates of the number of people with disabilities may be unreliable, the prevalence of disablement is cause for including disability in many sectors, such as health, education, and employment. Projects that benefit the general population should take into account the existence of disabled people in all target groups, even in cases when disabilities are not adequately reflected in the available data.

Annex Table 1. Main types of disability and their primary causes

| Type of disability | Proportion of people with disabilities (in percent) | Rate per 1,000 people | Main causes |
|---|---|-----------------------|---|
| Moving difficulties | 40 | 20–25 | Musculoskeletal disease, injuries/trauma, sequel after polio, hereditary conditions, cerebral palsy |
| Seeing difficulties | 15 | 5–8 | Measles, cataracts, glaucoma, trachoma |
| Hearing and speech difficulties | 15 | 5–8 | Meningitis, Rubella |
| Mental retardation/ learning difficulties, mental disorders, and epilepsy | 30 | 9–15 | Birth defects, genetic disorders |

Source: Einar Helander

Future Trends

Demographic and epidemiological transitions tend to increase the number of people with disabilities. The future trend in the numbers and proportions of people with disabilities will first reflect the general growth and aging of the populations.²⁴ Although aging (measured as the proportion of the population aged 65 or over) is growing concern to industrial countries, the number of elderly people is growing faster in developing countries than in industrial countries. From the service delivery point of view, the rapid increase in the numbers of potential clients due to aging is a major challenge, particularly in countries with a poorly developed health and social protection infrastructure. This phenomenon should make disability a priority for the health and social protection sectors of any human development plan.

Annex Table 2. Prevalence of disability²⁵

| Age | In less developed regions (In millions, year 2000) | In less developed regions (In millions, year 2035) | Change percent | In more developed regions (In millions, year 2000) | In more developed regions (In millions, year 2035) | Change Percent |
|-----------------------|--|--|----------------|--|--|----------------|
| 0–4 | 7.2 | 7.6 | + 5 | 0.86 | 0.85 | -1 |
| 5–14 | 27.4 | 30.4 | +11 | 3.93 | 3.40 | -14 |
| 15–29 | 27.3 | 35.1 | +29 | 5.11 | 4.41 | -14 |
| 30–64 | 101.4 | 214.8 | +112 | 36.94 | 38.99 | +6 |
| 65+ | 70.6 | 237.0 | +236 | 54.28 | 94.26 | +74 |
| Total (millions) | 233.9 | 524.9 | +124 | 101.08 | 141.91 | +40 |
| Percent of population | 4.8 | 7.0 | +46 | 8.5 | 11.8 | +39 |

The prevalence of moderate and severe disabilities due to aging is expected to increase by 46 percent in developing countries and by 39 percent in industrial countries by 2035. Furthermore, the global epidemiological transition will likely shift disease and disability patterns.

While infectious and communicable diseases remain the burden of the poor, the panorama is changing quickly due the recent large-scale medical interventions, such as immunization and nutrition programmes as well as curative interventions. Poliomyelitis is now almost eradicated and so is leprosy. This

²⁴ Helander (31). Also available online at: http://dag.virtualave.net/p_d.htm

²⁵ For more on the change of the disease pattern, see Christopher J.L. Murray et al., eds. *The Global Burden of Disease—A Comprehensive Assessment of Mortality and Disability from Diseases, Injuries, and Risk Factors in 1990 and Projected to 2020*. World Health Organization, Geneva. Summaries available online at: <http://www.who.int/msa/mnh/ems/dalys/intro.htm#figure1>.

will considerably lower the proportion of persons with mobility difficulties in developing countries. The incidence of blindness has been cut by measles immunizations and nutrition programs that have addressed vitamin A deficiency. Iodine distribution has lowered the incidence of mental retardation and sensorial disabilities. On the other hand tuberculosis and AIDS/HIV are increasing. Diseases such as unipolar mental disease and mental retardation are on the increase also in low-income countries. While this may be said also partly reflect improved diagnostic skills, the impact on service needs is obvious.

Communicable and most preventable diseases, when combined with malnutrition, are the leading causes of death and disability in the world. Respiratory infections, diarrheal diseases, and perinatal conditions were the top three causes of disease worldwide in 1990. The epidemiological transition is also causing a major shift in disease patterns. The role of communicable diseases is shrinking and that of noncommunicable diseases is growing.

According to World Health Organization estimates, the weight of heart and cerebrovascular diseases, psychiatric diseases, and road accidents will take the lead in the global burden of disease by 2020. Communicable diseases are and tend to remain, however, far more important to the poor than noncommunicable diseases. Therefore, from the poverty perspective, targeting investments in health for communicable diseases would still yield higher benefits to the poor.²⁶

²⁶ Davidson R. Gvatkin et al., "The Burden of Disease Among the Global Poor—Current Situation, Future Trends and Implications for Strategy" (Washington, D.C.:World Bank, 1999).

ANNEX 2. Summarizing Demand Characteristics and Required Service Responses

Governments, nongovernmental organizations, and individuals must determine the balance of preventive, curative, rehabilitative, or access and equality of opportunity dimensions of disablement that will be addressed in future human development policies.²⁷ The conceptual model of the “International Classification of Functioning, Disability and Health” helps to specify and clarify the focus of eventual interventions. The following table provides examples of types of interventions classified according to the ICF conceptual framework.

Annex Table 3. Interventions According to the “International Classification of Functioning, Disability, and Health”

| Challenge/Risk | Intervention | Impact |
|--|--|--|
| <ul style="list-style-type: none"> • Health risks, such as illnesses, violence, and accidents. • Social and economic risks. | Primary prevention, such as <ul style="list-style-type: none"> • Health promotion. • Human security improvements. • Preventive health care. • Environmental health. • Social risk management. | <ul style="list-style-type: none"> • Reduced incidence of disabling illnesses, violence, and accidents. |
| <ul style="list-style-type: none"> • Impairments, such as problems in body function or structure. | Impairment interventions, such as <ul style="list-style-type: none"> • Curative health care, surgery. • Secondary prevention (preventing activity limitations). | <ul style="list-style-type: none"> • Improved functioning in mental, sensory, communicative, physiological, and neurological. |
| <ul style="list-style-type: none"> • Activity limitations, such as difficulties in performance of activities (learning, moving, communicating). | Activity limitation interventions, such as <ul style="list-style-type: none"> • Rehabilitation. • Assistive devices. • Personal assistance. • Prevention of participation restrictions. | Improved independence in performing activities of daily living, such as <ul style="list-style-type: none"> • Learning and applying knowledge. • Communication. • Movement. • Orientation. • Self-care. • Domestic activities. • Interpersonal activities. |

²⁷ See also World Health Organization examples of service responses to disablement online at: <http://www3.who.int/icf/icftemplate.cfm>

| | | |
|---|--|--|
| | | |
| <ul style="list-style-type: none"> • Participation restrictions, such as problems an individual may have in the manner or extent of involvement in life situations (school, work). | <p>Equalizing opportunities through</p> <ul style="list-style-type: none"> • Awareness raising and sensitization. • Designing and implementing a policy toward a society for all. • Removing of social and economic obstacles for participation. • ADL training. • Facilitating participation. • Support services. | <p>Improved participation, Involvement, and contribution in various spheres of life, such as</p> <ul style="list-style-type: none"> • Personal maintenance and mobility. • Exchange of information. • Social relationships. • Home life and assistance to others. • Education. • Work and employment. • Economic, social, and civic life. |
| <ul style="list-style-type: none"> • Environmental barriers, such as obstacles in the physical, social, and attitudinal environment in which people live and conduct their lives. | <ul style="list-style-type: none"> • Equalizing access by removing barriers in the physical environment and adding products and technology in all social environments. | <p>Improved access to/usability of</p> <ul style="list-style-type: none"> • Products, technology, natural environment, humanmade environment. • Support and relationships. • Attitudes, values, and beliefs • Service systems. |

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